Patient Involvement in Germany – How and when?


German Agency for Quality in Medicine ÄZQ, Berlin
Patient Involvement

- patient involvement – why?
- guideline development in Germany
- methods
- results
- conclusions
Patient Involvement

- patient involvement in CPG assures and improves quality of health care.
- patient involvement is an important tool for guideline implementation.
Patient Involvement

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Guideline Development in Germany

No national institution for guideline development.

All scientific medical societies develop their own guidelines.
Guideline Development in Germany
guidelines registered and classified by the AWMF

National Guidelines Programs:

- National Disease Management Guidelines Program
- German Guideline Program in Oncology
Guideline Development in Germany

classification of guidelines according to AWMF

<table>
<thead>
<tr>
<th>S1</th>
<th>no systematic literature search</th>
</tr>
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<tbody>
<tr>
<td></td>
<td>no formal consensus process</td>
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</table>

<table>
<thead>
<tr>
<th>S2</th>
<th>systematic literature search</th>
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<tbody>
<tr>
<td></td>
<td>or</td>
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<td></td>
<td>formal consensus process</td>
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<table>
<thead>
<tr>
<th>S3</th>
<th>systematic literature search and assessment of the evidence</th>
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<tr>
<td></td>
<td>strength of guideline recommendation according to the level of evidence</td>
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<td>formal consensus process</td>
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Methods

The actual evidence-based guidelines (S2 and 3) have been assessed according to DELBI.

The guidelines have been assessed independently by two experts.

different results have been discussed.

the two experts have agreed about the final results.

Chicago, August 26th, 7th International G-I-N Conference, Corinna Schaefer, German Agency for Quality in Medicine, äzq
Domain 2, Question 5

“Patients’ views and preferences have been sought“

1 - patients are **not involved** or involvement has not been documented

2 - patients have been **involved indirectly** (i.e. by a review or public discussion)

3 - patients have been **involved directly** as members of the guideline development group

4 - decisional implications of patient involvement have been documented

**strongly disagree**  |  1  |  2  |  3  |  4  |  **strongly agree**
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Results I

patients involved?

N=152

- not involved
- indirectly
- directly
- contributions documented

- S3
- S2
- total

Chicago, August 26th, 7th International G-I-N Conference, Corinna Schaefer, German Agency for Quality in Medicine, äzq
Results II

a methodology of patient involvement?

6 guidelines with a defined methodology of patient involvement being part of German National Guideline Programs

N = 51
results III

patients were involved in guideline development in less than 35%.

in less than 5%, patient involvement followed a defined methodology.

the guidelines having a defined methodology of patient involvement were part of National Guideline Programs.
Patient Involvement

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Conclusions

Being an important implementation tool, patient involvement should become a standard in guideline development.

Especially in terms of transparency in nomination of patient representatives and funding, patient involvement should be based upon a defined methodology.

A defined methodology of patient involvement was found only within National Programs. Adaptation of this methodology by other guideline developers may enhance patient involvement in Germany.